**Developing and Growing the *Palliative Care Workforce* in Tasmania**

**PARTICIPANT INFORMATION SHEET (Family and Friends)**

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## Invitation

You are invited to participate in a research study examining how palliative care is provided in Tasmania and the ways that members of the community (paid and unpaid) who are involved in delivering palliative care may be better supported.

## What is the purpose of this study?

This project recognises that palliative care is provided by communities of people which include paid health care providers across different sectors (e.g. doctors, nurses, allied health, care workers) and unpaid care providers and support people (such as family carers, friends and volunteers).

This study is being undertaken to:

* Explore knowledge, attitudes and perceptions about palliative care,
* Gather feedback family member/friends about their contributions to in providing palliative care,
* Develop a series of actionable recommendations based on stakeholder feedback about what is needed for the future development and strengthening of palliative care in Tasmania.

## How is the study being funded?

This study is funded by Palliative Care Tasmania.

## Why have I been invited to participate?

You are eligible to take part in this study because you have been identified as a family caregivers or friend who has previously been involved in the delivery of palliative care (in the last 5 years) to someone with a life limiting illness across one or more of the following care sectors: hospital, community, disability and residential aged care. Your participation is voluntary, and your choice to take part or not take part will not affect any relationship you may have with either Palliative Care Tasmania or the University of Tasmania.

Please be aware that for this study we are not seeking the participation of family caregivers or friends who are currently providing palliative care (or those recently bereaved i.e. in the last 6 months).

## What will I be asked to do?

Participation in this study involves completion of an online survey and/or attendance at a two (2) hour online workshop with other family caregivers, volunteers and service providers. If you are unable to attend a workshop you may attend an interview.

***Online survey:***

The survey will ask questions about your knowledge, attitudes and perceptions about palliative care, as well as your opinion about current service provision. The survey should take no longer than 40 minutes to complete. Please note that submission of the completed questionnaire indicates your consent to provide your data for this research project.

***Stakeholder Workshop:***

The online stakeholder workshops will be held with stakeholders from Burnie, Launceston and Hobart using the zoom platform. Details on dates are available at the project website: <https://www.utas.edu.au/health/community-programs/palliative-care-project>

During the workshop you will be asked to share information about your current contributions to the provision of palliative care, the care networks that you are part of involved in the delivery palliative care, perceived barriers and enablers to developing more integrated care networks and ideas how stronger networks could be developed and sustained to support the delivery of palliative care in the state. The workshop will be facilitated by a member of the research team. As participants will be sharing information in a group setting, we will ask that you maintain confidentially about issues discussed and not share details of the discussions after the workshop. The workshop will be recorded so that a workshop summary can be developed. The facilitators will also check with participants that they have understood their comments and feedback correctly and you will have an opportunity to provide amendments or modifications during the workshop.

***Interview:***

If you are not able to participate in a workshop you can participate in an online interview with a member of the research team via zoom. This interview will address the same issues as the workshop and will take no longer than one hour. This interview will be audio-recorded in order to produce accurate field notes.

## Are there any possible benefits from participation in this study?

We cannot guarantee or promise that you will receive any benefits from this research, the knowledge and insights generated from the surveys, workshops and interviews will be used to inform future strategies to support palliative care workforce development and build communities of care in Tasmania.

## Are there any possible risks from participation in this study?

***Online survey:***

The only foreseeable risk is one of inconvenience caused by time taken to complete the survey. But if you find answering any of these question distressing, you can withdraw from the survey at any time.

***Stakeholder Workshop or Interview***

The foreseeable risks of participating in the workshop or an interview are:

* inconvenience due to time commitment of attending the data collection activity, and
* the possibility of mild discomfort for participants by being in a workshop or interview setting where you will be asked to share your opinions about palliative care and your involvement in the delivery of this service. To mitigate this risk we will ensure that you are provided with opportunities to freely share the information you wish, and to decline to share when you wish. We will use a range of strategies at the workshop (such as small group sessions, written feedback) to facilitate the comfort of our participants. You will be free to leave at any time. If you do experience discomfort associated with this project you can make contact with Lifeline 131114 <https://www.lifeline.org.au/crisis-chat/> or Beyond Blue 1300 22 4636.

## What if I change my mind during or after the study?

You may withdraw from the research at any time without consequence. This decision will not impact on your relationship with Palliative care Tasmania or the University of Tasmania However, if you complete and submit a survey and then chose to withdraw chose to withdraw it will not be possible to withdraw your data as it will be de-identified. Likewise, if you choose to withdraw after the workshop or interview, it will not be possible to withdraw your data as it will be de-identified. You may notify the Principal Investigator either in person if you are attending a data collection activity or via email or phone at other times if you wish to withdraw.

## What will happen to the data when this study is over?

**Online survey**

The survey will not collect any identifiable information from you and the data you share will be anonymous. The survey will be hosted on an online platform- Lime Survey. All information you provide is confidential and it will only be used for this project. It will be downloaded to in electronic format from the online survey platform and and be stored in password protected files on University of Tasmania server.

**Stakeholder workshop or Interview**

We will not collect any personal or identifiable information from you during the workshop or the interview.  All participants in the workshop will be explicitly requested to respect the privacy of other participants and maintain confidentially of the issues discussed. Data from the workshop will comprise field notes, where speakers will not be identified and any hard copy outputs from group work (i.e. electronic whiteboard copies). Interview audio-recordings will only be used for purposes of compiling field notes. All data from the workshops and interview will be allocated a code which will contain reference to the participant’s role, location and number (for example if you are a family caregiver in the community FCC1). Data collected will only be used for this project.

All data will be stored in electronic format (including consent forms, audio recordings, transcripts, fields notes and lime survey data) in password protected files on University of Tasmania server. Audio and Zoom recordings will be destroyed after the field notes have been developed. All other data will be stored five years from the completion of the project. Only the  Principal Investigator and members of the investigator team will have access to this data via a UTAS log in and password. At the end of the five-year period all data will be deleted.

## How will the results of the study be published?

It is anticipated that the results of this research project will be compiled into a report for Palliative Care Tasmania. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.  A summary of project findings will be available at the project website or by contacting Tas.pallcareproject@utas.edu.au

## What if I have questions about this study?

If you have any queries, concerns or issues with this study, please feel free to contact the Chief Investigator Dr Sharon Andrews, P: 02 85727936 or E: sharon.andrews@utas.edu.au. This study has been approved by the University of Tasmania Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, you can contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 6254 or email human.ethics@utas.edu. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H0026179.

1. **How can I agree to be involved?**

You can agree to being involved in a workshop or interview by signing the appropriate consent form and returning it to Dr Sharon Andrews Tas.pallcareproject@utas.edu.au Alternatively, you can register for a workshop or interview through the project website <https://www.utas.edu.au/health/community-programs/palliative-care-project> A member of the research team will make contact with you to confirm your registration and involvement. You may also directly contact Dr Sharon Andrews (see details above).

**Thank you for your time**